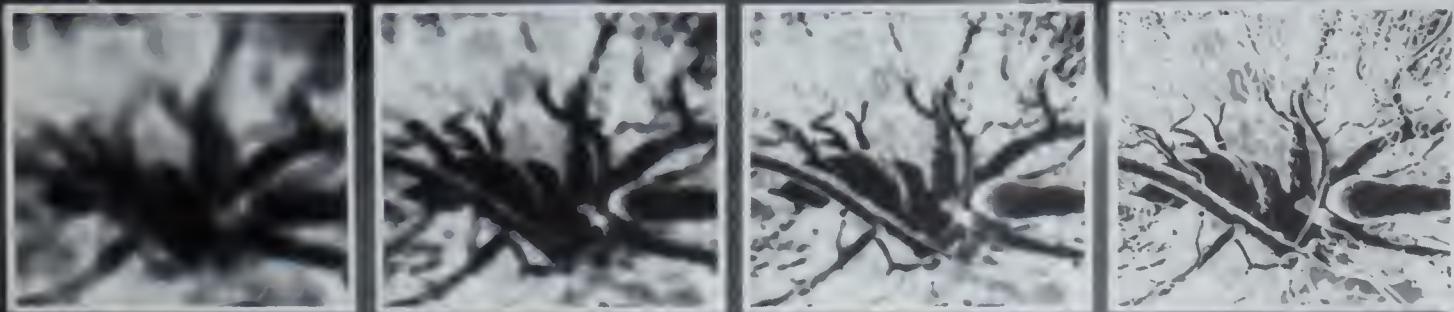
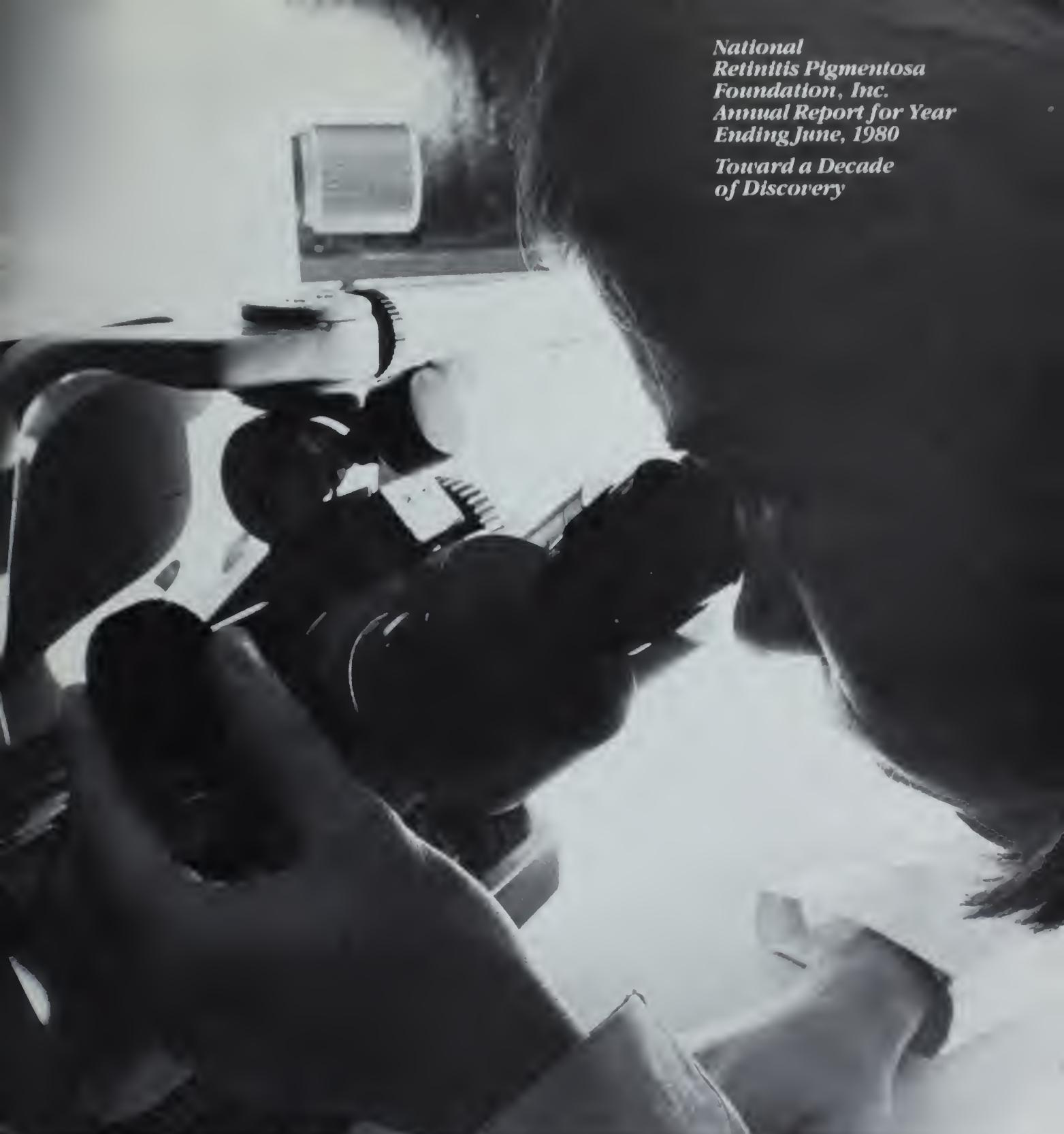


*National  
Retinitis Pigmentosa  
Foundation, Inc.  
Annual Report for Year  
Ending June, 1980  
Toward a Decade  
of Discovery*



### **On the Cover**

#### **"Toward a decade of discovery"**

Researchers can now perform quantitative studies of the optic nerve head, arteries, veins, and even the finest capillaries with three dimensional visualizations provided by the scanning electron microscope at the Wilmer Institute at Johns Hopkins Hospital. Such visualizations are extremely useful in studying Retinitis Pigmentosa, since changes in the appearance of the optic nerve head, as well as the adjacent retinal blood vessels, occur in the disease.

### ***The Mission***

The mission of the RP Foundation is the discovery of the cause, treatment and prevention of Retinitis Pigmentosa and other inherited retinal degenerations through research. Key to the success of this mission are cooperative scientific research, public awareness and professional education, both nationally and internationally. The RP Foundation will continue to initiate and support high-quality, focused scientific research, and information exchange overseen by the trustees and the National Scientific Advisory Board. This mission will remain in effect until a treatment and prevention is found.

The RP Foundation sponsors research into the following:

#### **Retinitis Pigmentosa**

Classified by inheritance as: Autosomal dominant, Autosomal recessive, X-linked, or associated with other abnormalities: Abetalipoproteinemia (Bassen-Kornzweig disease), The mucopolysaccharidoses, Refsum's disease, Usher's syndrome, Laurence-Moon and Bardet-Biedl syndromes. Cerebro-Retinal degenerations, (Batten's disease).

#### **Macular Degeneration**

Classified by age of onset and appearance as: Juvenile macular degeneration, Senile macular degeneration.

#### **Allied Retinal Degenerations**

Including: Gyrate atrophy, Chorideremia, Congenital achromatopsia, Stationary night blindness, Cone and cone rod degenerations, Albinism, Alipunctate dystrophy



## **A Message from the Board**

It is timely to take a short backward glance at our accomplishments as we approach our tenth year, in addition to assessing our present in-place capabilities for moving forward. The Foundation has grown to 42 chapters, 16 volunteer information resource centers, and over 22,000 volunteers. This network of people with purposeful dedication has participated in many discoveries over the years—all a necessary prelude to that major discovery we all await. As part of our overall research program and through our Scientific Advisory Board's oversight, we have provided direct funding support totaling \$614,982 to the following nine major research centers:

- Berman-Gund Laboratory for the Study of Retinal Degenerations (\$77,498)
- Wilmer Institute of the Johns Hopkins Hospital (\$72,121)
- Jules Stein Institute of the University of California (\$53,949)
- New York University Medical School (\$83,180)
- Baylor College of Medicine and the Hermann Eye Institute, both located at the Texas Medical Center in Houston (\$103,473)
- University of Illinois Hospital Eye and Ear Infirmary in Chicago (\$28,280)
- College of Physicians and Surgeons at Columbia University in New York (\$66,344)
- Medical College of Virginia, Virginia Commonwealth University, Richmond, Virginia (\$36,918)
- Jointly to the Institute of Ophthalmology, University of London and Moorfields Eye Hospital in England (\$93,219)

The present research program contrasts sharply with that of our first year of operation, when the Foundation's entire thrust was to





fund one multi-disciplined laboratory—and it took a total of three years to realize that goal.

We have grown rapidly and with due deliberation. We feel that now is a good time to evaluate our efforts and insure that we are as prepared as possible for our future work. As a first step to critically appraising ourselves and our direction, a Long Range Planning Committee of the Board of Trustees was formed in May, 1979 with a mandate to: (a) assess the RP Foundation's achievements to date; (b) evaluate motivating forces; (c) re evaluate overall goals and objectives; and (d) formulate strategic plans for achievement of goals. First, the Committee articulated our basic beliefs (what we are), and these then became the underpinning for development of the Foundation's mission statement (what we are about). This mission statement of the Foundation (on page 1 and below) serves as the guiding force for all efforts of the RP Foundation.

The following statement of our basic beliefs articulates what we are, and the following mission statement defines what we are about:

#### **Basic Beliefs:**

1. A treatment prevention for retinitis pigmentosa will be found through research.
2. Integrity and credibility must continue to be maintained throughout all Foundation functions.
3. National Trustees will continue to provide primary direction and guidance to the Foundation and its Scientific Advisory Board
4. Fundamental to the Foundation efforts are:
  - A. Cooperative scientific research
  - B. The volunteer chapter network
  - C. Fund Raising
  - D. Public Awareness
  - E. Human Services

#### **Mission Statement:**

The mission of the RP Foundation is the discovery of the cause, treatment and prevention of retinitis pigmentosa and other inherited retinal degenerations through research. Key to the success of this mission are public awareness and professional education, both nationally and internationally. The RP Foundation will continue to initiate and support high quality, focused scientific research and information exchange overseen by the Trustees and the National Scientific Advisory Board. This mission will remain in effect until a treatment and prevention is found.

Each large and small decision made by the Foundation will be guided by these statements of mission and basic belief.

As the following brief progress report reflects, the Foundation has made significant strides toward fulfilling its ambitious commitments. This is attributable to the hard work of volunteers throughout the organization and the dedication of a small, increasingly effective, professional staff.

#### **Research**

Since our last annual report we have not only provided initial funding for a projected fifth research center, but we have also identified and provided support for another four centers, thus, bringing the total centers supported to nine. Through the Retina Donor Program, we have continued to register RP donors who will their eyes after death to research on retinal degenerations. This program is opening new research opportunities, a major step in finding the causes of retinal degenerations.

We express our appreciation to the Eye Bank Association of America and the Medical Eye Bank of Maryland for their cooperation and assistance in this program.

### Fund Raising

In Fiscal 1979 we raised (unrestricted) \$912,351—\$33,671 more than the Foundation raised in fiscal 1978; in fiscal 1980, we raised \$1,129,773.

In our second year of participation in the Combined Federal Campaign (CFC), over \$53,000 was contributed to the RP Foundation by concerned Federal employees.

### Public Awareness and Education

Two national Public Awareness campaigns were designed and will be programmed in the Fall and Spring of each year (to coincide with Daylight Saving Time).

The theme of "There's an answer if only you'll help us find it: appeared on billboards, in magazines, newspapers, and even in transit and subway posters nationwide.

For the second time, the Foundation's campaign received support and recognition by the Ad Council through its "Bi-monthly Bulletin".

### Human Services

Providing adequate information and assisting with referral to services continue to be the primary goals of the Retinitis Pigmentosa Foundation's Human Services program.

The Foundation has developed a resource file of related professionals nationwide.

Working with established agencies and individuals around the country, the Foundation has assisted people with RP and allied retinal degenerations to find financial assistance, low vision aids and proper vocational rehabilitation.

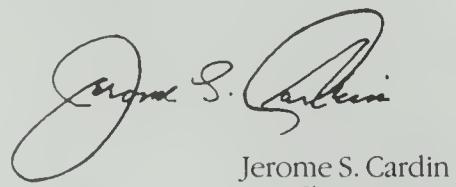
For the future we hope to accomplish the following:

- Pursuit of our research program including professional and

scientific oversight, coordination, and exchange of information on retinitis pigmentosa, macular degeneration, Usher's syndrome and other inherited retinal degenerative diseases, nationally and internationally, among the scientific community.

- Funding additional scientific pursuits which are determined by the Scientific Advisory Board to be applicable and meaningful to our overall effort.
- Formalization and implementation on a national scale of our Retina Donor Program.
- Expansion of our public awareness effort to provide: (a) national identification of the RP Foundation with daylight saving time (both in spring and fall); (b) more specific educational materials concerning retinal degenerations as needed; and (c) greater promulgation of the results of our research efforts to a broad audience in technical and laymen's terms.
- Emphasis will be placed on strengthening our overall organization, improving our programs and services for assisting chapters, and enhancing the efficiency of our fund raising capability.

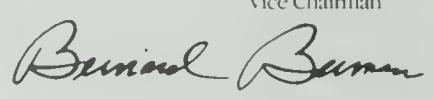
A great deal has already been accomplished, thanks to our volunteers, advisors, supporters and contributors. There is still much to accomplish, and we believe the Foundation is now equal to the greater task!



Jerome S. Cardin  
Chairman



Gordon Gund  
Vice Chairman



Bernard Berman  
President





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George L. Russell, Jr. 5, 7  
Allen Quille 8

- 1 Member of Executive Committee
- 2 Member of Chapter Relations Committee
- 3 Member of Public Awareness & Education Committee
- 4 Member of Convention Planning Committee
- 5 Member of Personnel Committee
- 6 Member of Finance Committee
- 7 Member of Audit Committee
- 8 Member of Fund Raising Committee
- 9 Long Range Planning Committee
- 10 National Scientific Advisory Board Liaison
- 11 National Human Services Advisory Board Liaison

## *"Toward a Decade of Discovery"*

### *Message from the Executive Director*

I welcome this opportunity to report on the progress of the RP Foundation during the fiscal year 1980. As the Foundation prepares to recognize its tenth year of commitment and challenge, we come to realize that discovery is a part of both our past and our future.

This was a year of particular achievement for the Foundation as we raised over a million dollars for the first time in our history. As a result, our support of research efforts this year was the highest ever. Although we raised 24% more funds we must remember that the 13% inflation rate cut deeply into our support of research grants. Although we now fund 59 investigators working internationally, the Foundation wants to continue to expand our commitments and continue our growth.

In the RP Foundation's second year of participation in the Combined Federal Campaign, we received over \$53,000 in designations from federal employees in 16 separate areas: Alabama; Arizona; Washington, D.C.; California; Colorado; Florida; Kansas; Massachusetts; New York; Ohio; Pennsylvania; Tennessee; Texas and overseas. The CFC Campaign is a program whereby federal employees at locations all over the world contribute to a listing of 23 national health agencies and other service organizations. Combined Federal Campaign collectively raises more than \$87 million for a broad range for health research within the U.S.

At the national level, we are pleased with the controlled growth of our staff and the manner in which they are helping to move one of the youngest national health agencies into a position of prominence. During the past year our human services program advanced in its capacity to serve both people with inherited retinal degenerations and their families in a variety of ways. We

have developed a comprehensive public awareness and education plan to reach countless people across the country.

The 42 affiliated chapters continued to be directed by a dedicated and hard working corps of volunteers. This effort, with the support of staff at the national level, enabled the Foundation to maintain its low fund raising and management expenses. The chapters launched a diversified fund raising program this year to reduce the focus on special events. The results produced a stronger support from the business community.

We are very proud of our track record so far, but the basic questions still remain: What causes retinal degenerative diseases? How can we treat them? How can we cure them? How can we prevent them? To move toward the answers during the next decade, we plan to take a number of important steps on many fronts. These steps will all require major financial commitments. We want to develop more centers for research, all cooperating, all working towards the same goal. We hope to increase the number of screening centers for the ITT Night Vision Aid. We want to expand our human service program and increase our chapter network to reach more people. And one of our highest priorities is to increase public awareness of these diseases and our work.

With all that we now have in the works and with a strong commitment to do even more, the decade ahead is a most promising and challenging one.



Dennis L. Hartenstine  
Executive Director





#### **Center Grants:**

The Berman Gund Laboratory for the Study of Retinal Degenerations at the Massachusetts Eye and Ear Infirmary, Harvard Medical School, Boston, MA

The New York University Medical Center, New York, NY

The Wilmer Institute of The Johns Hopkins Hospital, Baltimore, MD

The Jules Stein Institute of the University of California at Los Angeles, Los Angeles, CA

#### **1979-1980 Grants    1980-1981 Commitments**

Eliot L Berson, M.D., Principal Investigator; Ross B. Edwards, Ph.D.; Bernard Rosner, Ph.D.; Susan Y. Schmidt, Ph.D.; R. Bruce Szamier, Ph.D.; Michael A. Sandberg, Ph.D.	\$ 77,498	\$106,982
Ronald Carr, M.D., Principal Investigator; Harris Ripps, Ph.D.; Irwin Siegel, Ph.D.; Manoucher Shakib, M.D.	\$ 83,180	\$ 84,100
Daniel Finkelstein, M.D., Principal Investigator; Fred Fitzke, B.Sc.; James McDonald, Ph.D.; Robert Massof, Ph.D.; Irene Maumenee, M.D.; Magda Reissig, Ph.D.; O. Simmel, M.D.	\$ 72,121	\$ 79,252
Deborah Farber, Ph.D., Principal Investigator; Dean Bok, Ph.D.; David Chase, Ph.D.; Michael O. Hall, Ph.D.; John Heckenlively, M.D., Ph.D.; Richard Lolley, Ph.D.; Roberta Meyers-Elliott, Ph.D.	\$ 64,053	\$ 55,000



## **Center Grants:**

Institute of Ophthalmology, University of London,  
Moorfields Eye Hospital, London, England

College of Physicians & Surgeons, Columbia  
University, New York City, NY

Cullen Eye Institute, Baylor College of Medicine,  
Hermann Eye Center, University of Texas Medical  
School, Houston, TX

John Marshall, Ph.D., Principal Investigator;  
Alan Bird, M.D., F.R.C.S., Principal Investigator,  
Gillian Clover, W. J. Ernst, David Faulkner, Barry  
Jay, M. Jay, C. Kemp, D. Powell, Mary Voaden.

Peter Gouras, M.D., Principal Investigator,  
Mary Flood, Ph.D., James Haley

Joe G Hollyfield, Ph.D., Principal Investigator  
Charles A Garcia, M.D., Principal Investigator  
Roben F Anderson, Ph.D., Scott L Basinger, Ph.D.  
C. David Bridges, Ph.D., Jack T Holliday, M.D.  
Frank Kretzer, M.D., Dominic Lam, Ph.D., Richard  
Lewis, M.D., Linda Mewitz Levin, M.D.

Research

A strategy planning session by the Foundation's Board produced the very important re affirmation that research will provide the answers to the questions we ask about cause, prevention, and treatment of inherited retinal degenerations. A research list follows which illustrates all research grants supported by the Foundation to date.

We are witnessing a remarkable development of research on retinal degenerations all over the world. To a significant degree, this is a result of the actions taken by the RP Foundation and a greater awareness on the part of the ophthalmic research community to the importance of investigating and studying retinal degenerations. The awarding last year of five additional center grants effectively doubled the Foundation's research effort.

In keeping with the principles of our research program, all grantees are at institutions where the condi-

<b>1979-1980 Grants</b>	<b>1980-1981 Commitments</b>
\$95,000	\$110,000
\$60,344	\$65,151
\$103,473	\$125,000

tions are appropriate for the development of a broad-based research focused on retinitis pigmentosa, macular degeneration, Usher's syndrome and other hereditary retinal degenerations. Where possible, the Foundation undertakes a shared responsibility—nearly all grantees simultaneously hold research grants from the National Eye Institute. By this means, the Foundation serves a catalytic role, either in the initiation of a new research effort or in the expansion of one already established, while at the same time sharing responsibility for scientific review and financial support.

The RP Retina Donor Program is a critical part of our research program. Though the RP Retina Donor Program is just getting underway, research findings of significance can be attributed to it. It is increasingly clear to us that, if there is to be a breakthrough in the understanding of degenerative diseases of the retina, there must be an effective retina donor program.

Although hundreds of thousands of children and young adults are affected by retinal degenerations, very few human eyes have even been studied. We feel certain that the eyes which are donated to the Foundation will provide opportuni-

ties to our researchers that cannot be obtained in any other way so that the vision of others can be saved. In addition, the donation at death of eyes from relatives who themselves do not have retinal degenerations will be studied for comparative research analysis.

To register with or receive additional information on the RP Retina Donor Program, mark the space on the enclosed envelope or on the inside back cover and the Foundation will send you the appropriate material.

#### **Scientific Advisory Board**

Alan Laites, M.D.  
Chairman

Morton F. Goldberg, M.D.  
Secretary

Mathew Alpern, Ph.D.  
Bernard Becker, M.D.  
Edward Cotlier, M.D.  
John Dowling, Ph.D.  
Jay M. Enoch, Ph.D.  
Gerald E. Fonda, M.D.  
Robinson Harley, M.D.  
Richard M. Hill, Ph.D.  
Ruth Hubbard, Ph.D.  
Wayne Hubbell, Ph.D.  
Matthew LaVail, Ph.D.  
Arnall Patz, M.D.  
Richard L. Sidman, M.D.  
George Wald, Ph.D.  
Richard Young, Ph.D.

#### **Center Grants:**

University of Illinois Eye and Ear Infirmary,  
Chicago, IL

Medical College of Virginia, Virginia Commonwealth Univ., Richmond, VA

#### **Other Activities:**

Animal Facility

Scientific Workshop

#### **1979-1980 Grants      1980-1981 Commitments**

Gerald Fishman, M.D., Principal Investigator;  
Jose Cunha-Vaz, M.D.; Rockefeller S. L. Young, Ph.D.  
Roger L. Klingaman, Ph.D.

Walter E. Nance, M.D., Ph.D., Principal Investigator;  
Joann Boughman, Ph.D., Principal Investigator

For the acquisition, care and distribution of dogs  
with hereditary retinal degenerations. The dogs are  
kept at Federated Medical Resources, Honeybrook,  
PA

Scientists doing significant research in this area  
from around the world were invited to Toronto to  
discuss their past, present and future efforts.

\$ 28,280      \$ 32,637

\$ 36,918      \$ 54,923

\$ 20,000      \$ 25,000

\$ 40,000

# *A Living Tribute*

*RP Foundation*

*There is an answer...  
If you'll only help us find it.*

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## **Remembrance - Memorial Fund**

At the request of those who wish to give tributes, the Retinitis Pigmentosa Foundation has established a Remembrance - Memorial Fund. This tribute to someone loved means others are helped thru research. Every gift gives hundreds of local children and adults a better opportunity to see more . . . longer.

Gifts may be sent to the Fund for the happy occasions of birthdays, anniversaries, holidays and other special days deserving thoughtful tribute. Gifts are also appropriate upon the death of a friend or relative.

When such gifts are received, the RP Foundation will promptly send an appropriate acknowledgement to the person honored, or the relatives in the case of memorial contributions. The name of the donor or donors will be stated, and the purpose of the gift, but the amount will not be mentioned. Each donor will receive a personal acknowledgement.

*Your contribution to the RP Foundation is tax deductible. Please insert check here. ▶*

*Reina Donors Needed:* If you desire to participate in the RP Foundation's Reina Donor Program or want more information, please check here

If more of these tribute envelopes are desired, please indicate here

Your *Remembrance* or *Memorial Gift* to the *RP Foundation* may be made by providing the following information and mailing your check, payable to *RP Foundation*, in this envelope.

Amount of Gift.  
\$5      \$10      \$15      \$25      \$50      \$100      Other

Full name and address of person to whom *Remembrance* or *Memorial Card* is to be sent. Indicate how you wish this card to be signed.

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Full name and address of person(s) making this gift to the *RP Foundation*.  
(A receipt acknowledging this gift will be sent to this donor).

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Check One:  In Honor Of:  In Memory Of:

Name of deceased person in whose memory this contribution is given or  
name of person(s) being honored.

Please type or print

*Retinitis Pigmentosa Foundation*

8331 Mindale Circle  
Baltimore, Maryland 21207

Your Stamp  
Here



Iea Hyvarinen, M.D., Finland

Mark W. Bitensky, M.D., Yale University

#### **Professorships:**

Manoucher Shakib, M.D., The NYU Medical Center, New York, NY

#### **Fellowship:**

Ido Perlman, Ph.D., Hadassah University Hospital, Jerusalem, Israel

#### **Career Development Award:**

Samuel G. Jacobson

To produce video tape on special ophthalmic needs of deaf individuals

Biochemistry of the dystrophic dog retina

#### **1979-1980 Grants    1980-1981 Commitments**

\$1,252.00

\$5,000.00

\$18,000

(Included in  
NYU — \$83,180)

\$53,933

(Included in  
NYU — \$84,100)

\$11,000

Training program in ocular psychophysics and physiology in preparation for career in RP research

\$39,282.00

## **Human Services**

Our human services effort throughout the country provides vital information to medical and scientific professionals, lay persons, and families and friends of those with retinitis pigmentosa and other retinal degenerations. Education is an important support area for accomplishment of our mission: Education on the overall impact of retinal degenerations, the availability of low-vision aids and internal and external support services.

In an effort to identify specific areas and methods of possible assistance that are available to persons affected by retinal degenerative diseases, a reference file continues to be developed which includes numerous advocates, agencies, organizations and clinics serving the visually impaired nationwide. This includes educational and health services as well.

Payment by health insurance firms in California and Ohio for the partial purchase of the ITT Night Vision Aid on behalf of persons with RP marked a significant event. This aid manufactured by ITT Corporation continues to help more persons with RP to live productive and meaningful lives. ITT not only produces the night vision aid at cost to individuals with RP but also provides substantial support to the overall research effort of the Foundation to find the cause, prevention and treatment of inherited retinal degenerations.

## **ITT Night Vision Aid**

The ITT Night Vision Aid continues to provide independence, confidence and mobility to individuals with RP who are unable to see at night (night blindness) but who still maintain some vision in daytime.

The device originally developed by ITT with the Army's Night Vision Laboratory actually amplifies light levels to make them effective to people with RP.





The electronic aid has now been distributed to people in 27 states nationwide.

For more information on the Night Vision Aid, write directly to Night Vision Aid Distributors, Inc., P.O. Box 207, Randallstown, MD 21133.

The following screening centers in the U.S. and Canada will test individuals for the possible use of the medical aid, which may be ordered only by prescription:

#### **Screening Centers**

Eliot L. Berson, M.D. Director, Berman Gund Lab  
Harvard Medical School, MEEI  
243 Charles Street Boston, MA 02114  
617 523 5656

Harold E. Cross, M.D., Ph.D.  
Professor and Head Section of Ophthalmology  
The University of Arizona  
Tucson, AR 85724 602 626 6264

Eleanor Faye, M.D.  
The New York Assoc. for the Blind  
(The Lighthouse)  
111 East 59th Street New York, NY 10022  
212 355 2200

Daniel Finkelstein, M.D.  
Johns Hopkins Hospital Wilmer Institute  
The Woods Research Bldg. Rm. 267  
601 North Broadway Baltimore, MD 21205  
301 955 3429

Samuel M. Genensky, Ph.D.  
Director, Center for the Partially Sighted  
Santa Monica Hospital Med. Cen.  
1250 Sixteenth Street Santa Monica, CA 90404  
213 451 1511

John Heckenlively, M.D.  
Jules Stein Eye Institute  
800 Westwood Plaza Los Angeles, CA 90024  
213 825 6089

Wayne F. March, M.D.  
Low Vision Center Dean A. McGee Eye Institute  
608 Stanton L Young Drive Oklahoma City, OK  
405 231 6060

John A. Parker, M.D., F.A.C.S. (C)  
Suite 105, University Wing Toronto General Hospital  
Toronto, Ontario MSG 1L7 Canada 416 597 0004

Franklin I. Porter, O.D.  
Baylor College of Medicine The Cullen Eye Institute  
6501 Fannin Houston, TX 77030 713 790 5935

William W. Vallotton, M.D., F.A.C.S.  
Director, Storm Eye Institute  
Medical University of South Carolina  
171 Ashley Avenue Charleston, SC 29403  
803 792 2492

Mitchell Wolf, M.D.  
Jewish Hospital of St. Louis  
216 South Kingshighway P.O. Box 14109  
St. Louis, MO 63178 314 554 7887

## **Volunteer Network 42 Chapters,**

The largest amount of funds raised by the RP Foundation (60%) continues to come from the Chapters. Over 22,000 volunteers in 42 local Chapters were actively involved with special events, membership drives and federated campaigns.

Volunteers continued to discover new mechanisms for raising funds for research through special benefit programs. During the last fiscal

year, volunteers rode bicycles (in Rhode Island) horses (in Cleveland) and race cars (in North Carolina and other chapters) to raise funds. They choreographed dinner dances in Manhattan and Los Angeles and stayed at home (for profit!) in Chicago. In Baltimore and New Jersey, RP volunteers went to the movies while Connecticut held its annual Marching Drum and Bugle Corps competition. Orange Countians and Long Islanders played golf while in Alabama, volunteers played a special baseball game for RP

research. Washingtonians walked while Floridians skated for sight. In Miami, volunteers formed a 250 Club for both fun and profit. A big fund raiser continues to be the ad journals associated with a variety of these events. These were but a few of the imaginative fund raisers held all over the country.



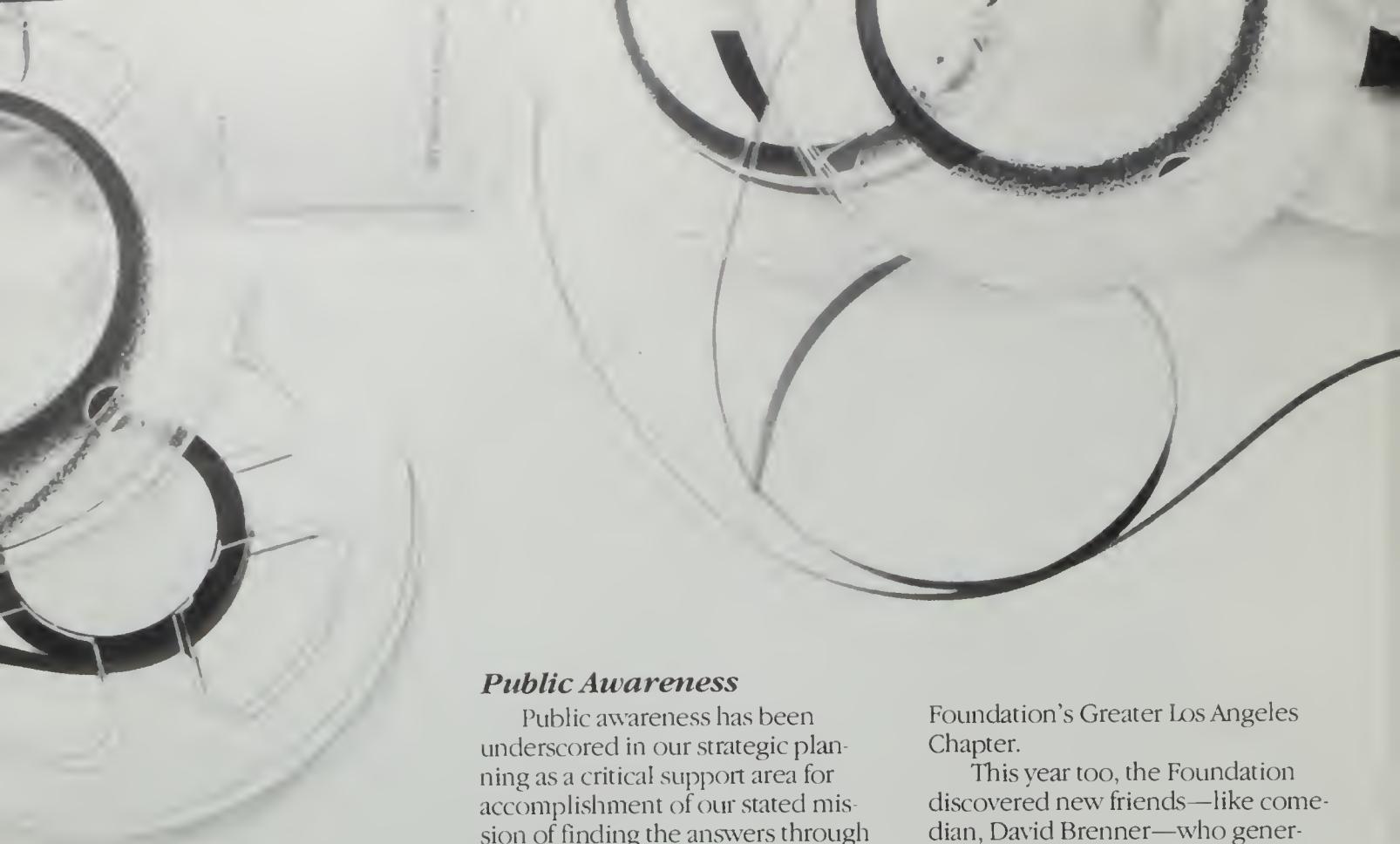
In addition, annual and life memberships were further increased through a coordinated effort of both the National office and local Chapters.

Furthermore, Chapter members continue to work hard at public awareness by stimulating local and national publicity for the Foundation, and serve as support mechanisms for other people with retinal degenerations by sharing experiences and information.

### ***Volunteer Information Resource Centers (16)***

In those areas where there are no Chapters, Volunteer Information Resource Centers (VIRC) were established to assist persons with retinal degenerations. VIRC's are a step along the way to the development of new chapters. New VIRC's were established in Tulsa, Oklahoma, Pittsburgh, Pennsylvania, Niagara Falls, New York, and Fort Worth, Texas.





## **Public Awareness**

Public awareness has been underscored in our strategic planning as a critical support area for accomplishment of our stated mission of finding the answers through research.

Two coordinated national public awareness campaigns chaired by National Honorary Chairman Ben Gazzara have been designed and planned each year to coincide with daylight savings time—one in the spring and one in the fall. Also, a travelling exhibit has been developed which will be shown around the country at professional and medical meetings. During the past year, over 29,000 people have had an opportunity to learn about the Foundation through this exhibit.

With the overwhelming support of the Foundation's Sports Chairman, superstar Richard Petty, and a committee composed of Cale Yarborough, Darrell Waltrip and Bobby Allison, "Races for Sight" have been held around the National Association for Stock Car Auto Racing (NASCAR) circuit.

David Doyle, star of "Charlie's Angels" and his wife Anne, who has RP, brought additional attention to the Foundation's efforts with their appearance on "Good Morning, America". The Doyles are also heavily involved in the efforts of the

Foundation's Greater Los Angeles Chapter.

This year too, the Foundation discovered new friends—like comedian, David Brenner—who generously volunteered to assist in the Foundation's Public Awareness campaign during the coming year.

To bolster the Public Service efforts even further, Steve Allen and his wife, Jayne Meadows, produced several television public awareness spots for both retinitis pigmentosa and Usher's syndrome. Beverly Sills set the machinery in motion for another RP benefit concert—this one held in Birmingham, Alabama. Ron Guidry and Reggie Jackson of the New York Yankees, Brooks Robinson (former Oriole), quarterback Ken Stabler of the Houston Oilers, and Bert Jones of the Baltimore Colts Foundation. Sports commentator Vin Scully has volunteered his time to the Greater Los Angeles Chapter on many occasions.

"The Celebrity Family Feud" TV game show contributed over \$17,000 to the Foundation through the enthusiastic efforts of the stars of "Three's Company": Norman Fell, Audra Lindley, John Ritter, Susanne Somers, and Joyce Dewitt and "The Ropers".

With the help of our new Director of Public Information,



our future public awareness programs will be better planned and coordinated, and chapters will be provided with even more professional public awareness materials and assistance than ever before.

Plans for the National Public Awareness Program in the future include: development of a national speakers bureau, continued cooperative effort with the AD Council, more information exchange between chapters and national, and other ways to bring news of our work and needs to as broad an audience as possible.



*David & Anne Doyle*



*Beverly Sills*



*Billy Crystal*



*Vin Scully*



*George Gobel*



*The Bee Gees*



*Darrell Waltrip*



*Tom Brokaw*



*Charlton Heston*

## Treasurer's Report

In fiscal 1980, total combined unrestricted revenues of national headquarters and its affiliated chapters amounted to \$1,129,773, a 24% increase over fiscal 1979. This growth was made possible by the dedication and commitment of our volunteer network and the contributions of many individuals, foundations and corporations. Unrestricted program expenses increased 57% over 1979 from \$662,627 to \$1,037,969. This increase is due in large part to additional research grant awards made in fiscal 1980 as we continue to expand our support of research activities both nationally and internationally.

We are very proud to report that of the unrestricted revenues received in fiscal 1980, 92% was expended for our program services (including 60% for research), 11% was expended for management and general expenses and only 6% for fund raising expenses. The total of these percentages exceeds 100% due to the \$103,616 deficit resulting principally from the increase in research grants awarded in fiscal 1980.

Total public support and revenues for fiscal 1980 is approximately \$1,000,000 greater than in fiscal 1979. Such increase includes \$630,000 relating to a restricted gift awarded to the Foundation to establish a professorship of ophthalmology for the study of retinal degenerations at Harvard University. Restricted research expenses for fiscal 1980 include a \$700,000 grant awarded by the Foundation to establish this professorship.

The Board of Trustees has approved planned research expenditures approximating \$2.4 million for support of awards and grants to research facilities and other specific research programs through 1983. Expenditures under research programs in fiscal 1980 were significantly greater than in fiscal 1979 as we established four additional

research centers. Since our available unrestricted funds as of June 30, 1980 of \$1,494,859 fall short of our planned research expenditures, the Foundation has launched a major fund-raising campaign to obtain the resources needed to continue and coordinate our research efforts.

Our combined financial statements have been prepared in conformity with generally accepted accounting principles for voluntary health and welfare organizations and have been audited by Peat, Marwick, Mitchell & Co., independent certified public accountants.

The Retinitis Pigmentosa Foundation meets the standards of the National Information Bureau and the eligibility criteria set forth by the Office of Personnel Management for participation in the Combined Federal Campaign. The Foundation's programs continue to be recommended to the media by the Advertising Council, Inc.

The national headquarters budget is reviewed and approved by the Board of Trustees.



Sallie W. Cushner  
Vice President and Treasurer

RESEARCH  
9%

Due to the deficit incurred by the increase in research grants, total exceeds 100%.

**How the dollar was spent**  
by National Headquarters  
and Chapters in  
FY 1979-1980

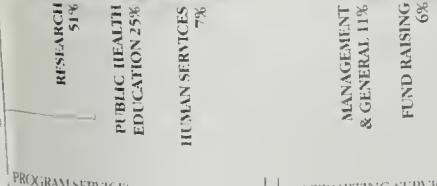
NATIONAL RETINITIS PIGMENTOSA FOUNDATION, INC.  
AND AFFILIATED CHAPTERS

**Combined Statement of Support, Revenue and  
Expenses and Changes in Fund Balances**

Year ended June 30, 1980  
with comparative totals for 1979

	1980			Total all funds
	Current funds	Building and equipment fund		
	Unrestricted	Restricted		1980 1979
<b>Public support and revenue:</b>				
Public support:				
Contributions received from individuals, corporations and foundations	\$ 563,193	758,407	5,630	1,327,230 595,822
Special events, net of direct costs of \$232,255 in 1980 (\$166,160 in 1979)	393,603			393,603 235,921
Total public support	956,796	758,407	5,630	1,720,833 831,713
Grant from governmental agency		17,980	—	17,980 28,045
Interest income	172,977	18,185	—	191,162 138,311
Total public support and revenue	1,129,773	794,572	5,630	1,929,975 998,099
<b>Expenses:</b>				
Program services				
Research	679,277	75,859		1,405,136 435,336
Public health education	277,222	23,211	2,607	303,040 157,715
Human services	81,470	16,211	521	98,202 93,018
Total program services	1,037,969	765,281	3,128	1,806,378 686,069
Supporting services				
Management and general	128,117	39,745	1,565	169,427 99,302
Fund raising	67,303	1,779	521	69,603 34,666
Total supporting services	195,420	41,524	2,086	239,030 133,968
Total expenses	1,233,389	806,805	5,214	2,045,408 820,037
Excess (deficiency) of public support and revenue over expenses	(103,616)	(12,233)	+16	
<b>Other changes in fund balances</b> — office furniture and equipment acquisitions from unrestricted current funds				
Fund balances at beginning of year	(7,717)		7,717	
Fund balances at end of year	1,606,192	94,154	17,742	
	\$1,494,859	82,221	25,875	

For a complete copy of the audited combined financial statements as of and for the year ended  
June 30, 1980, please write to the National Office.





## **Bequests . . . A Legacy Of Life**

Bequests of all sizes help make possible the research and educational activities of the RP Foundation. The Foundation's record of careful management insures the enduring usefulness of funds entrusted to its care. You can assure the Foundation of continuing financial support by using the following bequest form.

*"I give and bequeath to the National Retinitis Pigmentosa Foundation, Inc., a corporation organized under the laws of the State of Maryland, the sum of \_\_\_\_\_ dollars for its corporate purposes."*

Like all other gifts to the Foundation, bequests by will of money, securities, a house, other real or personal property, the residue of an estate, or any part of it are, of course, tax deductible. Before a donor makes a gift of substance, he should consult his attorney. You may also write to the Foundation:

National Retinitis Pigmentosa Foundation, Inc.  
8331 Mindale Circle  
Baltimore, Maryland 21207  
301-655-1011

### **Are you registered?**

If you have retinitis pigmentosa or another retinal degenerative disease and have not completed the National Registry Form, please cut out the card below, check the appropriate box and return to the RP Foundation.

The Registry is important in helping the Foundation gather statistical data to better understand these diseases. All information is confidential.

**For more information . . .** about the Foundation and retinal degenerations, cut out the card below, check the appropriate box and return to the RP Foundation.

Your contribution to the National Retinitis Pigmentosa Foundation, Inc. is tax deductible

Cut Here and Enclose in Tribute Envelope

- Send Retina Donor Information
- Send Information on IIT Night Vision Aid
- Send a Confidential Registry Form
- Send Additional Information on RP and other Retinal Degenerative Diseases.

If you wish additional copies of the Annual Report for your personal distribution, please indicate the number here:

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State \_\_\_\_\_ Zip \_\_\_\_\_

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**Retinitis Pigmentosa**  
**Foundation, Inc.**  
**8331 Mindale Circle**  
**Baltimore, Maryland 21207**  
**301-655-1011**  
**TTY-301-655-1190 (for deaf)**

